Achieving Excellence in
the National Health Care Survey

Open Space Forum

Division of Health Care Statistics
National Center for Health Statistics
Centers for Disease Control and Prevention

Hyattsville, Maryland
February 8–9, 2005

The Division of Health Care Statistics has been engaged in a process to plan the future directions of the Division and its family of surveys that constitute the National Health Care Survey. The Division's senior staff held a brainstorming retreat in October 2004, and all Division staff and certain other staff from the National Center for Health Statistics (NCHS) took part in an Open Space meeting in November 2004 that raised ideas about improving our surveys and working arrangements. The Open Space Forum of the larger community held February 8-9 was part of that overall planning process.

A broad range of users and potential users of our surveys and partners and potential partners from diverse fields and organizations, including professional societies, academia, foundations, quality-improvement organizations, government, and consumer advocacy, who had backgrounds in medicine, nursing, public health, economics, statistics, sociology, law, health services research, and policy analysis, joined Division and other NCHS staff in discussing wide-ranging topics. Over the two-day Forum, the individual participants convened one-hour sessions on topics that they thought important for the Division and the larger community. These proceedings relate the discussion that took place and the actions that the participants suggested. We are following up on these suggestions, and incorporating them in our planning efforts.

We greatly appreciated the participation and thoughtfulness of everyone who attended. Our thanks also goes to Steve Cochran, www.leadershipresults.org, International Centre for Leadership Results, Gettysburg College, who facilitated the Forum, and coached us on the Open Space approach.

                                        Jane E. Sisk, Ph.D.
                                        Director, Division of Health Care Statistics

Contents:

SESSION TITLE: Linking Data To Improve Value

CONVENER: Michael Fitzmaurice and Paul Eggers

HEADLINES: (Discussion and Recommendations)

- **How do we link data? Methods, opportunities?**
- **Current projects underway include Center for Medicare and Medicaid Services (CMS) and NHANES ?? (with Social Security number)**
- **Process NHANES and NHIS and Social Security data – lots of review of officers of agencies**
- **Spending years undertaking the link – date of birth, Social Security number and provider – give and take on potential matches.   Make determination on matches.**
- **Talk about linking Medicaid data, Medicare data, private insurance data**
  Possibly initiate a process for linking all these databases.
  How do we make these data available for use and increase links?
- **Medicare data has some easy linkages – cost reports, FIPS codes**
- **How do we get improved access around IRBs?**
- **Why is NCHS more difficult to get data from?**
- **Provider ID#s are going to be standards – goal to understand physician practice patterns**
- **Lots of privacy problems**
- **How do we link nursing home data from patient to providers?**
  Is it difficult? If you don't have federally sponsored research, then it is very difficult.
- **Census Bureau is creating synthetic data sets to test their hypothesis then they pursue their research proposals to get user agreements, etc.**
  "Synthetic data" - Census links the data and then deidentfies the data sets.
- **Who is in the business of making data available to researchers? What are the obstacles to public use? (example of NIH process to make data available)**
- **Centers for Medicare and Medicaid Services – Medicare Modernization Act Sec 723, Chronic disease registry, get NIH to fund and make a new link and new partnerships.**
- **Potentially have an IRB review data sets**
- **Cannot override the promise to collect the data and then use it for multiple purposes.**
- **NCHS**
  Can do provider link and person link.
  Possible to get physician provider number.
- **Get Medicare data, link to NHCS – link it inhouse.**
- **Do not have the same linkages across NHCS data sets – nursing homes collect Social Security # where others do not.**
- **Medicaid number and American Hospital Association (AHA) ID are used to link.**
  Agreement with AHA to link data to National Hospital Discharge Dataset
  Linking at hospital level data is possible.
- **Patient level data are much more difficult – AHRQ**
- **Depending on state, physicians may also be tracked…**
- **NCHS is trying to summarize Medicare data and make them publicly available.**

- **HCUP – you must sign data use agreements**
- **Why are we doing this? Break out of the unit of observation.**
  Link to track over time, physician visit to claims data.
  Aggregate up – therefore some linkages are helpful while others are not helpful.
- **Drug Databases- for drugs**
  MedSTAT – data from self-insuring employer; link inpatient, outpatient and drug data. Dataset on benefit design characteristics is being developed.
- **Barrier –   ??? for NHIS staff**
  Can you certify users in a regional level so that you do not have to make trips to Hyattsville and Rockville to use the data?
- **Currently – data use legislation, (CIPSEA??)**
  New law about linking data – yet to be tested, thought to be more restrictive
- **Whom are we increasing value for – NCHS?? the Public??**
  There are limited resources – are we truly increasing value? Does it justify the increased risk to privacy??
- **Understand lab datasets. Indianapolis is currently putting this into place.**

ACTION ITEMS: (Declarative Statements)

Technical approaches, legal issues, etc., need to resolved by working together to identify ways to share datasets.

1. **Create a list of linked data files that can be made available to everyone.**
   a. **Interagency and outside partners should be at the table to create this list.**
   b. **Possibly convene a forum – involve the Institute of Medicine or other group to make this happen.**
      Commission IOM to study this issue.
      National Committee on Vital Statistics could potentially convene this group.

2. **Find ways in addition to the Research Data Center to access NCHS data sets relatively easily from outside of NCHS, without having to travel to Hyattsville, Maryland.**

3. **NCHS should look to Census about developing synthetic datasets.**

4. **NCHS should develop a model for costs and benefits of linking these files? What is the value added?? What are ethical/privacy issues involved?**

5. **What do national provider IDs mean for NAMCS data set?**

6. **Focus on home health care survey – Can you follow patients from home health care settings to other settings?? Link to CMS data and see where they end up.**

Attendees:

1   Michael Fitzmaurice
2   Jerry Riley
3   Paul Eggers

4	James Lubitz
5	Clark Paramore
6	Bill Marder
7	Amy Chanlongbutra
8	Donna Vallone
9	Tim Carey
10	Dionne Braddix
11	Charlie Adams
12	Chet Bowie
13	Paul Hebert
14	Jeremy Brown
15	Steve Wilkins
16	David Matchar
17	Bob Pokras
18	Mike McNeil
19	Elayne Heisler
20	Claudia Steiner
21	Judy Ball
22	Susan Schappert
23	Alyssa Keefe
24	Merilyn Francis
25	Jane Sisk
26	Jill Marsteller

SESSION TITLE: Physician Workforce Studies: Supply, Demand and Use of Physicians

CONVENER: Edward Salsberg

HEADLINES: (Discussion and Recommendations)

- **How many doctors will the nation need in the future?**

- **We need to measure services by physicians and how our health care needs are changing.**

- **Is it appropriate to consider NAMCS an appropriate data source for this need?**

- **The sample size for this survey is too small for physician specialty details.**

- **Can we link with any other external administrative data sets?**

- **What is the effect of other health care provider types on physician practice patterns?**

ACTION ITEMS: (Declarative Statements)

1. **Explore possibility of linking NAMCS with other external data sources.**
2. **Consider collaborating with specialty physician groups to design and conduct studies.**
3. **Explore external funding through physician specialty group.**
4. **As electronic medical record (EMR) becomes part of practice, explore the potential to use data from EMR for the survey.**
5. **We support the inclusion of community health center physicians in the survey.**

Attendees:

1	Edward Salsberg
2	Elizabeth Howell
3	Ann Greer
4	David Woodwell
5	Sara Thran
6	Julia S. Holmes
7	Morgan Jackson
8	Dale Lupu

SESSION TITLE: Effect of Advanced Technology on Quality and Access to Care

CONVENER: Molla Donaldson

HEADLINES: (Discussion and Recommendations)

- **Better integrated data are needed to support technology assessment, evaluation, and research – particularly to support policy.**

- **Electronic health record will change the NCHS surveys' role and usefulness – with that assumption, what should NCHS do? Lead in standardizing? Dissemination? White papers to raise issues?**

- **There would be common ground to work with others (i.e, Kaiser, VA) – if there is a "grand plan" by an "honest broker".**

- **What barriers would there be to an integrated system? (e.g., HIPAA, vendors, lack of standardized data elements/definitions)**

- **Should we start with questions that will need to be answered and then design the system? Think more broadly than health policy – labor, housing, etc.**

- **Data from patients will still be needed – more than establishment data.**

ACTION ITEMS: (Declarative Statements)

- **NCHS must determine their role in meeting future data needs, assuming that their current surveys will no longer be needed.**

- **NCHS must strategically plan for 5 – 10 years ahead.**

- **NCHS should take the lead in developing a system to integrate data sources (e.g., genomic, encounter, cancer registry) – for public use. Is NCHS the "honest broker"?**

- **NCHS should take steps now to position themselves – for example, white/thought papers, raise the questions to the policy level, exploring linkages with private sector (e.g., KP), learn from experiences of other countries, etc.**

- **NCHS should take the lead in working across agencies to determine data needs, issues, innovations, etc.**

Attendees:

1   Molla Donaldson
2   Howard Isenstein
3   Deneen Richmond

4   Trena Ezzati-Rice
5   Tom McLemore
6   Jean Kozak
7   Marcel Salive
8   Meg Johantgen
9   Cathy Schoen
10 Marjorie Greenberg
11 Robert Brook

SESSION TITLE: Collecting Information on Alternative Residential Care Facilities

CONVENER: Bill Marton

HEADLINES: (Discussion and Recommendations)

- **No one definition of assisted living or residential care**

- **Approach now is to include entities licensed by the state, and exclude settings providing care for MRDD and behavioral health populations. (State-level data on licensure and certification are the starting points.)**

- **Who is left out by using the above approach (e.g., persons receiving long term care in an adult foster care arrangement)?**

- **Unit of sampling is initially the provider, then perhaps the resident (modified version of old nursing home approach before minimum data set (MDS). Focus groups are also done for collecting recipient-level information.**

- **Stratification based on:
  Facility size
  Payer source-% of private insurance, Medicaid, self-pay
  Market variation (e.g., nursing home ratio)**

- **Goal is to make national estimates but could also over-sample a subset of states with impact of state policy/regulation-
  Acuity rules
  Numbers of assisted living recipients
  States with low, medium and high acuity**

- **Differences in free-standing vs. affiliated/system providers**

- **There are differences in urban/metro areas vs. rural/small town**

- **Information to collect-
  Skilled and non-skilled staff
  Residents with dementia, depression
  Population characteristics- gender, race, age
  Services needed
  Drugs received
  Chronic illness**

- **Partnerships and other research opportunities:
  Foundations may fund supplemental work
  Assisted living facility membership organizations (four include less than half of the assisted living facilities)
  Center for Excellence in Assisted Living (CEAL)**

ACTION ITEMS: (Declarative Statements)

1. **The Federal Government should periodically field a national survey on residential care/assisted living facilities and their residents.**

2. **Consideration should be given to a sample design that would allow some state estimates as well as national.**

3. **Consideration should be given how to design and collect data at the resident level.**

4. **Surveys should be designed to make policy-level estimates, considered in sampling and analysis. Link regulations with providers and residents.**

5. **Survey efforts should build upon existing work and build partnerships with other organizations.**

6. **This will not be a "perfect" survey, and will improve over time.**

7. **Partnerships should include public and private stakeholders.**

8. **Some long term care populations will not be addressed by initial survey efforts.**

Attendees:

1	Bill Marton
2	David Kyllo
3	Fred Decker
4	Todd Gilmer
5	Sylvia McSkimming
6	Beth Han
7	Genevieve Strahan
8	Abbie Moss
9	Dianne Feeney
10	Judy Kasper
11	Robin Remsburg
12	Harriet Komisar
13	D.E.B. Potter
14	Lisa Dwyer
15	John Drabek

SESSION TITLE: Linking Data into Episodes of Care

COVENER: Sharon Arnold

HEADLINES: (Discussion and Recommendations)

- **Information on episodes of care at the person level is important for measuring the effect of care on "outcomes."**

- **It is easier to get information from one provider than to "cross" providers…but even more information on the same person from a given provider would be useful.**

- **Nursing home and home health are already more "episode-like" and contain more information at the person level than hospital discharge or ambulatory care visits.**

- **Could the field representative (FR) or designated provider go back and collect specific information on visits prior to the "sampled" visit?**

- **It would be difficult to sample specific conditions or procedures and still maintain a national sample. However, the national sample could be supplemented with previous visits (that is, FR or a provider designee could determine the person sampled and go back and sample previous visits using the same form).**

- **Prospective data collection at the provider level would be more difficult, because it would require multiple visits to the provider, and the provider or FR would have to keep track of visits from previously sampled persons. They would probably be less willing to do this than to abstract information on multiple visits from the same person at one sitting.**

- **FRs (or hospital staff) might also be able to abstract information on multiple hospitalizations at the same hospital for a given person, although only in hospitals where data are collected manually. A revised data collection methodology might be warranted to collect more information on a person at a hospital over a period of time (including rehospitalizations, drugs, clinical information, etc.).**

- **"Process" quality of care measures could be collected. A list of these measures that could be used to help assess quality of care in different settings could be developed in consultation with others.**

- **Information on admission and discharge disposition that could be correlated with these process quality measures should be collected.**

- **Selected clinical indicators useful in evaluating quality of care should be included in the encounter-level information. There should be some consensus on what measures are most important, and the periodicity of measures. (Do we need blood pressure, height and weight on every visit? Do we need every measure every year? If we need to combine years, the same measure should be collected in both years, etc. A committee could develop 5 or so indicators that should be collected on an annual basis and others that could be rotated on and off the survey instruments).**

- **Encounter level data can be useful, because it provides information on what happens during encounters that cannot be as accurately reported by patients, and because less common conditions and diagnoses are included in the data. Not all issues can be addressed by MEPS-like person-level interviews. However, the more encounters per person that can be collected, the better able the analyst is to evaluate quality of care provided (at the person level).**

- **Obtaining more patient-level demographic and other information would be useful, but can be difficult to obtain directly from medical records. Linkage might be desirable, or follow-back studies to patients (although the group understands the expense and confidentiality issues associated with conducting these studies).**

  - **Oversampling specific conditions or procedures would affect the overall representativeness of the sample, and should not substitute for the national samples of encounters. However, they could be added to the national sample if resources permit, and then specific clinical or therapeutic data elements could be collected relevant to those conditions or diagnoses.**

  - **Questions on provider procedures associated with quality (Do they claim to provide obesity, or smoking, or health habits counseling? What are their criteria for referring for specific procedures or tests? Do they monitor patient compliance, and how? How do they notify patients of results? Etc.) could be added to the provider induction forms.**

ACTION ITEMS: (Declarative Statements)

- **For NAMCS/NHAMCS/NHDS, collect retrospective information on visits/discharges made by the person whose visit/discharge is sampled. For example, using the same encounter form, abstract additional visits made previously by the person at the same provider within the last [time] period. The sampled visit would still be used to make national estimates, but the additional information could be used to create an episode of care provided at that particular doctor's office, outpatient department, emergency department, or hospital.**

- **Include specific clinical information relevant to quality of care (determined by clinicians and others) at regular (although not necessarily annual) intervals.**

- **If possible, link visit-level information to other data (e.g., minimum data set (MDS) to nursing home data). There are confidentiality issues, but if they can in some way be overcome, it would enhance the usefulness of the data.**

- **Investigate the possibility of follow-back studies to obtain outcomes.**

- **Add questions on provider practices associated with quality of care to the provider induction forms (where applicable).**

Attendees:

1   Sharon Arnold

2   Carina Deans
3   Gail Daumit
4   Ernest Moy
5   Marni Hall
6   Amy Bernstein
7   Linda McCaig
8   Donna Vallone
9   Cathy Burt

SESSION TITLE: How Can Non-Federal Users and Supporters Support NCHS?

COVENER: Tim Westmoreland

HEADLINES: (Discussion and Recommendations)

- **Focus on infrastructure to support national data system is needed. This should be a public sector role and priority.**

- **NCHS must look at itself and identify areas for coordination, collaboration. Congress may perceive surveys as duplicative, agencies divided into turf areas.**

- **Many organizations depend on NCHS data to understand their own industries, support their positions.**

- **A Congressional briefing, initiated by these organizations, could be beneficial. This will help them understand what data are produced. Congress does not pay for what it does not understand.**

- **Some organizations are not aware that the data they are using come from NCHS.**

- **Short term briefings plus long term focus on infrastructure.**

- **NCHS analysis tends to be somewhat limited. Standard reports mean that findings get buried within a report. There is a need for more in-depth analysis. Who should do this more in-depth analysis? NCHS or the research community? Or both?**

  - **Is NCHS the gatherer or the analyzer of the data? Risk of politics in science. How should NCHS prioritize areas for in-depth research?**

- **NCHS should not sacrifice timeliness of data release because of analysis.**

- **Getting more policy researchers to understand and use data is important. Better marketing of surveys is needed so that researchers are familiar with them.**

- **People think of the NHCS as provider surveys, but do not recognize the value for policy. (They think it is counting nursing homes and physician visits.)**

- **There is increasing concern about the lack of data for disparities and quality. Researchers may not be aware that NCHS data can address these concerns.**

ACTION ITEMS: (Declarative Statements)

- **NCHS should identify who uses its data and how. (Maybe focus group at AcademyHealth)**

- **Identify obstacles researchers face in using NCHS data, perhaps through a survey of HCFO or other researchers. Is it that they don't know about the surveys, or that the surveys do not collect data that are useful?   Is there a cost barrier to using these data?**

- **Research funders should be thinking of ways to make their grantees familiar with data that are available.**

- **Convene a session (at AcademyHealth's annual research meeting or the Policy Conference, for example) that combines funders, data systems, and researchers to scope out ideas for future research.   Session could be jointly funded.**

- **NCHS should look for one on one opportunities at specialty society and trade association meetings to showcase key findings from existing surveys.**

- **Convene an educational Congressional briefing to help staffers become familiar with NCHS data.   Seek opportunities to work with organizations such as the National Health Policy Forum to disseminate topic-related findings.**

- **Outside and government agencies need to work together to understand data linkage issues, sort content and responsibilities, define and ensure collection of essential data elements, and work toward a national data infrastructure.**

Attendees:

1   Tim Westmoreland
2   Linda Bilheimer
3   Rob Weinzimer
4   Irma Arispe
5   Jane Sisk

SESSION TITLE: What Clinical Data Should the Emergency Room Survey Collect?

CONVENER: Jeremy Brown

HEADLINES: (Discussion and Recommendations)

- **Some of the items on the current emergency department (ED) patient record form are not useful, and could be deleted, so that others may be substituted. More specificity about certain items should be collected.**

- **Electronic data collection should be explored to save costs and improve timeliness. Time spent coding could be eliminated through electronic data collection. (DAWN choses drugs from a list.) Does not limit one to a 7 ½ X 14 piece of paper. SAMHSA's Palm experience was that it took a long time to look through a drug list (12,000 names).**

- **Duplication in efforts to collect ED data exist (National Hospital Ambulatory Medical Care Survey (NHAMCS), Drug Abuse Warning Network (DAWN), and (NEISS)).**

ACTION ITEMS: (Declarative Statements)

- **Consider adding or deleting the following items to or from the patient record form for EDs in the 2007 NHAMCS:**

  - **Obtain data on ED visits resulting in hospital admissions, and link these to the inpatient records, to obtain data on the episodes of care (NCHS started doing this in 2005 to some extent).**

  - **Add an item on how many times the patient has visited the ED in the last 6 months or year?**

  - **Obtain lab values for complete blood count (CBC), creatinine, hematocrit, and cardiac enzymes to assess severity.**

  - **Add toxicology screen, and specify whether it is for blood or urine.**

  - **Specify the types of CT scan and MRI ordered, e.g., head or abdominal.**

  - **Specify whether thrombolytic therapy is for the heart or brain.**

  - **Add a checkbox to indicate if the patient was obese or used tobacco.**

  - **Delete blood pressure and pulse, as the former cannot be used as a measure of hypertension in this setting.**

- **Observe a demonstration of the DAWN electronic data collection.**

- **To have one data collection system for all hospital-related data, the federal government should select about 500 sentinel hospitals that would provide data for NHAMCS, National Hospital Discharge Survey (NHDS), National Survey of Ambulatory Surgery (NSAS), DAWN, and NEISS).**

Attendees:

1. Linda McCaig
2. Judy Ball
3. Jeremy Brown
4. Bob Pokras
5. Mike McNeil
6. Meg Rohantgen
7. Claudia Steiner
8. Bill Marder

SESSION TITLE: Making Data More Uniform and Accurate To Increase Value

CONVENER: Michael Fitzmaurice

HEADLINES: (Discussion and Recommendations)

- **Data translation often needed to achieve uniformity between various coding systems.**

- **Health insurance coverage is especially tricky.**

- **Data translation can be expensive and time consuming, takes a lot of resources.**

- **HL7 model discussed – every variable has a header, computer can sort out, electronic messaging system – but no one is globally responsible for what an admission or discharge means, for example.**

- **SNOMED – vocabulary reference – translator – maps different terms to common concept – very important for quality of care issues.**

- **ANSI accredits bodies that produce standards – government agencies have been known to provide funding for producing standards.**

  - **Data accuracy – is the reported diagnosis accurate? Can validate through analysis of other data collected.**

- **Standards can create rigidity, may not take into account changes in treatment, do not reflect changing technology because codes may not be developed for new devices, etc.**

- **Data elements are defined differently at the source (in physician offices, etc.), so even with things like OMB standards used in our encounter forms, it is difficult to achieve uniform data definitions.**

ACTION ITEMS: (Declarative Statements)

1. **Add some kind of registry to datasets to identify problem areas?**

2. **Build software solutions to make things less labor intensive in data translation projects.**

3. **Have someone responsible for assigning code values in a timely manner.**

4. **Organize the structure – define the data elements in a standardized fashion.**

5. **Need an official set of here is what the variables mean and here is how they are coded.**

6. Alternative to standardization is achieving common reference map like SNOMED, but need lots more money to achieve this uniformity.

7. NCHS could explore working with AHRQ and CMS on achieving consensus on categories.

8. Increase NCHS participation in standards developing organizations.

9. NCHS can call in health services researchers, epidemiologists, clinicians to agree on most important data elements/definitions.

10. NCHS needs more money to increase accuracy of data through validation studies.

11. NCHS should work within the Department to move from ICD-9 to ICD-10.

12. Encourage survey participants to use common and specified definitions.

Attendees:

1 Bill Marder
2 Trena Ezzati-Rice
3 Chet Bowie
4 Dionne Braddix
5 Gail Daumit
6 Sally Gousen
7 Jean Kozak
8 Susan Schappert
9 Michael Fitzmaurice
10 Steve Wilkins
11 David Woodwell
12 Elayne Heisler
13 Julia Holmes

SESSION TITLE: Determinants of Successful Use of Data in Policy Formulation

CONVENER: David Matchar

HEADLINES: (Discussion and Recommendations)

- **The surveys provide important data for policy making, for example, baseline information, show how drug influences clinical outcome, data can influence decisions to get a drug on a formulary.**

- **Cross sectional data provide important link to cost, resources (annual use of resources has to be estimated with NHCS surveys). More data on resource use would be beneficial. Linked data from claims may make data even more useful.**

- **Has NCHS done research to see who is using data and how?**

- **Is the general purpose nature of data reasonable, or should the surveys focus on more specific policy questions?**

- **Examples of how data can be used for policy.**
- **National data are useful for assisting coverage decisions, framing the issue, identifying magnitude of the problem, potential uptake of the technology.**
- **There is not a lot of descriptive data on process of care (for diagnosis of Alzheimer's, for example).**
- **These surveys provide a comparator (for the below age 65 population, for example). Effect of policy on a population. You can broadly assess impact of policy for periods before and after the policy.**
- **Data are used to describe context. Context supports more detailed studies (sets framework for the disease, for example)**
- **Identify types of medications prescribed for children.**
- **Data are useful to identify problem of antibiotics use and resistance, decline in use of antibiotic prescribing following CDC educational program aimed at physicians.**
- **In quality improvement, many decisions are made at the state level. (Policy options at the state level include mandated reporting, link payment to performance.) National data assist problem identification, early in the process (before indicator development).**
- **State Medicaid decisions are driven by (1) a powerful anecdote and (2) conversion to dollars.**
- **Issues in making data more policy relevant.**
- **Data should be relevant, but not at the expense of timeliness.**
- **NCHS performs essential data functions. (There are other organizations do policy).**
- **NCHS should remain free of special interests.**
- **Tailored surveys can be problematic, because policy issues change.**
- **Strategic release of data keeps you relevant, but there is some political risk involved.**
- **NCHS is well positioned for a bipartisan approach to providing health data.**
- **General purpose surveys seem to work well; it is hard to anticipate upcoming policy issues.**

- **Advent of electronic medical record means that encounter based surveys will not be that useful in the future. NCHS needs to adapt so it will not become extinct.**

- **Examples of policy research: How much waste is in the health care system? What proportion of drugs for children are off label? How are chronic diseases treated in the health care system? NCHS can do this because it is nonpartisan.**

ACTION ITEMS: (Declarative Statements)

- **NCHS needs to engage in a 5-10 year strategic planning process. NCHS needs to identify important policy questions, map data collection to answer these questions, make strategic decisions based on that matrix (and make this information available to the public, Congress). Rationale for collection of data should be clear.**

- **NCHS needs to focus on quicker release and more "real time" data.**

- **NCHS should be active in sorting out where nation-wide data (vs. sentinel surveys) are needed. NCHS should focus on issues like data coordination, targeting emerging issues such as bioterrorism.**

Attendees:

1 Irma Arispe
2 Cathy Burt
3 Ann Greer
4 Marcel Salive
5 Amy Chanlongbutra
6 Clark Paramore
7 Bruce Stuart
8 Rob Weinzimer
9 Tommy McLemore
10 Dianne Feeney
11 Marni Hall
12 Sara Thran
13 Tim Westmoreland
14 Sharon Arnold
15 David Matchar
16 Jane Sisk

SESSION TITLE: Improving Quality of End-of-Life Care – What Data Do We Need?

COVENER: Dale Lupu

HEADLINES: (Discussion and Recommendations)

- **Look at measures that can be used across surveys and providers that will measure end-of-life care and allow comparison across settings.**

- **We need another national mortality follow back quality survey (and how could you link this to provider survey info?).**

- **Incorporate Joanne Lynn's work on quality measures into survey.**

- **Looking at quality of end-of-life care in all settings**

ACTION ITEMS: (Declarative Statements)

- **Need a descriptive picture of what is emerging in other models of palliative care.**
- **Need to incorporate IOM report recommendations.**
- **A hole – there are no national data on bereavement care.**
- **Policy issues: access to care, changes in financing of hospice, quality of end-of-life care across settings, nursing home – hospice payment issues, what models of care work or are cost effective**
- **Need a high level white paper/expert panel to look at the big picture – what policy questions we need answered, what data we need, where to get that data. Incorporate the IOM report findings into this. Incorporate the National Quality Forum work on quality measures.**
  Look at national dataset of the National Hospice and Palliative Care Organization (NHPCO) – what partnership possible?

Attendees:

1 Dale Lupu
2 Carina Deans
3 Abbie Moss
4 Sylvia McSkimming
5 Lisa Dwyer
6 Beth Han
7 Genevieve Strahan
8 Robin Remsburg
9 Jerry Riley
10 Paul Eggers
11 Tim Carey
12 Merilyn Francis
13 Judy Kasper

SESSION TITLE: Collecting Data on Quality of Life and Customer Satisfaction in Surveys

CONVENER: David Kyllo

HEADLINES: (Discussion and Recommendations)

- **Web based surveys are possible as well as many other technological survey tools; get away from the paper and pencil surveys**

- **Is a core set of questions possible or to what degree does it need to be adjusted to individual utility?**

- **How do you define quality and quality of life? Is it the role of the public health system to improve quality of life beyond health concerns, e.g., having a good place to live?**

- **Using modern measurement theory will be important (Promise Road Map).**

- **How responsive is quality of life to the setting or the intervention? We should move in this direction, but we need to keep in mind the purpose.**

  - **In long term care settings, staff satisfaction correlates to quality of life and resident settings.   How do you create the survey so that it actually could translate into action steps for the provider?**

- **We should be measuring health related quality of life in surveys. It is preferable to collect that information directly from residents/patients. Where that is not possible, proxy measures should be considered.**

- **Is quality of life measurement retrospective surveying, or should the measures be done as part of the clinical practice? Need to understand the purpose of the data collection.**

- **Customer experience may be more important than customer satisfaction. Also expectations play a huge role. (Avoid the term "satisfaction". Go with "experience."**

ACTION ITEMS: (Declarative Statements)

1. NCHS should incorporate customer satisfaction/experience items into their ambulatory based surveys.

See Headlines for additional recommendations.

Attendees:

1   Fred Decker
2   Paul Herbert

3   David Kyllo
4   Elizabeth Howell
5   Marjorie S. Greenberg
6   Todd Gilmer
7   Howard Isenstein
8   Cathy Schoen
9   Molla Donaldson
10 D.E.B. Potter
11 Morgan Jackson
12 Deneen Richmond

SESSION TITLE: How Can NCHS Catapult Quality Improvement in the U.S. Health Care System?

CONVENER: Dianne Feeney

HEADLINES: (Discussion and Recommendations)

- **NCHS data are used to formulate the problem.**

- **What are physician-sensitive measures? What measures are useful for physicians?**

- **Physicians are moved by data, but not utilization data. The need for information beyond the visit "dilutes" the importance of the visit data that are collected.**
  How can make event data have more meaning for quality?
  Identify activities that should be done at every visit, or for patients with a given diagnosis.

- **"Duplicating" data collection can be useful as a check, or for comparative purposes.**

- **What would make data more useful for quality? Identify problems, provide benchmark/baseline relative to national averages.**

  - **Can the surveys look at systems of care? (Reminder systems, coordination of care, Bridges to Excellence (BTE))? Is there a way to use the survey to duplicate the types of information that are collected as part of BTE, so that national data can be compared to regions and practices?**

- **Can the surveys ask physicians how they measure the success of their own care?**

- **Is it possible to look at the system (to see if providers deliver appropriate care for given types of patients)? Collect data that would focus on what needs to change in the system to improve care for all patients.**

- **If measures are about "patients getting appropriate care", rather than focusing on a specific disease, this might make the measures more acceptable and improve care for all patients.**

- **In the hospital environment, there is a movement toward condition specific measures plus cross cutting measures (for example, surgical infection prevention measures), or measures that pertain to things that should never occur (wrong site surgery, for example).**

- **Is it possible to look at characteristics of the hospital to look at their association with quality?**

ACTION ITEMS: (Declarative Statements)

1. **NCHS should consider collecting:**

Information on systems of care to look at quality.
Nurse sensitive measures (American Nurses Association pilot hospitals are collecting these data, but the measures are not necessarily uniformly operationalized, so standardized national data could be helpful).
Cross cutting measures to look at quality.
Hospital characteristics.

2. NCHS should explore ways to get meaningful data to physicians to push the quality agenda. This could include more clinical data and/or use of national data for comparative purposes. If claims data and survey data tell the same story, it is a stronger story.

Attendees:

1   Dianne Feeney
2   Julia S. Holmes
3   Molla Donaldson
4   Ernest Moy
5   Irma Arispe
6   Elizabeth Howell
7   Amy Chanlongbutra
8   Cathy Schoen
9   Jill Marsteller
10 Dionne Braddix

SESSION TITLE: Electronic Health Records and Impact on Administrative Survey Data

CONVENER: Claudia Steiner and Trena Ezzatti-Rice

HEADLINES: (Discussion and Recommendations)

- **Electronic health record (EHR) implementation presents challenges and opportunities for NCHS. What data will still be needed (e.g., getting Rx vs. filling Rx vs. taking drug)? Who will not be represented (e.g., individuals with no contact with health system)?**
- **General consensus that the EHR has the potential to improve and streamline data collection efforts for the study and analysis of health care. The EHR, however, will not replace the need for data collection efforts to continue to study and improve the health care system.**

- **Still need classification systems and data standards to support EHR (e.g., device codes).**

- **Assuming that EHR would support reimbursement system, how will this work and will this influence what data will be collected? (e.g., patient fear of releasing information. Who would have right to release information (e.g., life insurance actuarial models?)**

- **NHANES may be a good place to start to think about other data elements that are needed.**

- **Most focus on EHR has been how to take care of individual patients – not research or policy focused. While coverage is broader and cost of data collection decreased, it may be harder to use, have elements that are not reliable and valid, etc.**

  - **The role of government is to create the electronic highway so EHR can travel across insurers, locations, etc.**

- **Assuming EHR will collect descriptive information, NCHS surveys could focus more on drill down issues, conditions, etc.**

ACTION ITEMS: (Declarative Statements)

NCHS should define key items/data that are needed to make EHR more useful – and identify the classification systems so they are coded the same way.

NCHS should set up expert meetings to take advantage of Federal agencies, private, and international experiences in EHRs.

NCHS should take a lead in the reliability and validity investigation of EHR.

NCHS should begin to do some examination of EHR systems to investigate some of the above issues (reliability, missing data, etc). - not wait for a critical mass of implementation.

NCHS should examine where cost data will come from – if not EHR? (e.g., MEPS goes to providers).

Attendees:

1. Michael Fitzmaurice
2. Cark Paramore
3. Trena Ezzatti-Rice
4. David Woodwell
5. Susan Schappert
6. Paul Eggers
7. Steve Wilkins
8. Linda McCaig
9. Elaine Heisler
10. Claudia Steiner
11. Meg Johantgen
12. Ann Greer
13. Mike McNeil
14. Sharon Arnold
15. Bill Marder
16. Marni Hall

SESSION TITLE: Improving Data Availability for Home and Hospice Care

CONVENER: Carina Deans

HEADLINES: (Discussion and Recommendations)

- **Need to collect discharge data so can get episode of care in hospice**

- **Collect data on patient symptoms – pain and shortness of breath, how well managed - for both hospice and home health**

- **Untangle home, hospice, and combined.**

- **Look at National Hospice and Palliative Care Organization (NHPCO) national dataset to see what data elements they are collecting.**

- **Cost of service important.**

- **Look at visits or encounters – explore how Centers for Medicare and Medicaid Services (CMS) counts visits, although per diem payment for hospice.**

- **Now is the time for field to provide input into the survey.**

- **Move toward future – electronic data collection. National sample of agencies to become corps source of data over time?**

Attendees:

1   Carina Deans
2   Genevieve Strahan
3   Abbie Moss
4   Fred Decker
5   Merilyn Francis
6   Lisa Dwyer
7   Dale Lupu
8   Beth Han
9   Sylvia McSkimming

SESSION TITLE: How To Better Describe Efforts at Disease Management in Populations

CONVENER: Todd Gilmer

HEADLINES: (Discussion and Recommendations)

- **Disease management is a non-specific term.**

- **Who is paying for it? Is it in house? Is the primary doctor involved?**

- **What are the clinical characteristics of a disease management program that let us know how the patient is being managed?**

- **Is it possible to get a sense of the penetration of disease management into the practice?**

- **Nurse case manager, follow up, behavior modification, drug evaluation, coordination with physician, screening, peer classes, registries, reminders.**

- **Wide range dependent on disease – some intensive (dose response), some programmatic.**

- **Is someone else engaged in the care: PBMs, independent companies, etc.?**

- **Propose a list be developed that would allow us to get some indicators about how disease management affects the provider –patient relationship.**

- **Referral question (that patient that day) move to tell how collaborative it is?**

- **Focus on chronic conditions – probably a limited set of diseases you can document.**

   - **Prompts and reminders that are disease specific, registries.**

   - **Should this be a NAMCS module, person-level survey (NHIS), or its own survey (sample DM firms)?**

   - **Specialization of the participants may vary.**

ACTION ITEMS: (Declarative Statements)

Include 2 sets of questions in the next NAMCS module (or facility level):

1. **What is being done: Ex: Does a DM program use: prompts or reminders, registries, nurse case manager, peer groups, drug modification.**
2. **Who or what is doing the managing, and what is the level of integration with the primary care practice. Ex: Is the DM program on site? Does the provider receive**

enough information from the DM program to improve the clinical care of the patient?

Attendees:

1 Judy Kasper
2 Tim Carey
3 Paul Hebert
4 Jean Kozak
5 Jerry Riley
6 Cathy Schoen
7 Todd Gilmer

SESSION TITLE: NCHS' Primary Public Purpose Should Be To Provide Real Time Data To Navigate the Health Care System

CONVENER: Robert Brook

HEADLINES: (Discussion and Recommendations)

- **NCHS should take leadership role to facilitate the public's use of the health care system. Right now it is all done by the private sector. For purpose of helping people make good, timely decisions about their use of health care. Empower consumers—to give them information to make decisions about their health care—quality of care, etc.**

- **Issues/obstacles: confidentiality/privacy; costs—larger samples, etc., needed for local decision-making.**

- **Leadership in state of the art vs. leadership in collecting data? Setting standards, making data more usable? Clearinghouse of data? Guidance on developing methodology for transparency; leadership in identifying measures of quality of care.**

- **NCHS should take leadership role in providing options, advantages and disadvantages of options, identifying sources of information to help consumers decide where to go for care.**

- **NCHS should at least explore how to provide information on individual providers and institutions.**

- **Role of NCHS is trustworthy, because it does not have a stake in policy outcome.**

- **NCHS must reinvent itself if it is to be relevant 10 years from now –in environment with electronic medical record. NCHS needs to be more relevant to the users of information, and do so in a way that does not threaten its role as a trustworthy neutral party and is consistent with protecting confidentiality.**

- **This would require NCHS' partnering with private sector institutions.**

- **NCHS could provide more in-depth information about health—i.e., with older population, NCHS could find out about typical behaviors of older people and their attitudes about aging, etc.**

- **Pick an issue for doing this on trial basis: quality of care for cancer patients? Quality of primary care? Choose 4 or 5 common chronic conditions and build data system to report on these (can do this by using current NCHS data systems, and also by partnering with other sources of data). Perhaps hypertension as example.**

- **So, overall headline is NCHS as the data expert needs to think about how to be relevant in changing world—using its expertise to provide comprehensive answer to questions about health and health care system. Perhaps start with one example, such as hypertension. Start with step of asking, "What's the quality of care for**

hypertensive patients in 2005." Consider issues including equity, patient safety, other "aims" in IOM report.

ACTION ITEMS: (Declarative Statements)

Attendees:

1 Jane Sisk
2 Rob Weinzimer
3 Marjorie Greenberg
4 Marcel Salive
5 Gail Daumit
6 Robert Brook
7 David Matchar
8 Molla Donaldson

SESSION TITLE: How Can the Health Community Improve Public Attitudes Toward Survey Participation?

CONVENER: Sally Gousen

HEADLINES: (Discussion and Recommendations)

- **HIPAA has been a roadblock to getting patient information.**
- **It is becoming customary to provide some level of incentive pay to respondents Hospital Survey and Census), $40 to $100.**
- **Census now keeps a contact history as others do.**
- **People have concerns about identify theft as well as far less time to respond.**
- **Whether the agency had a letter of endorsement from the state association made a huge difference – not just the national association.**
- **There has been a decline in the # of respondents for the national nursing home survey.**
- **Financial incentives do not work for all groups (docs, etc.)**
- **AHRQ calls the incentives reimbursements for the respondent's time and effort.**
- **The CDC had great success with a web based survey working with the trade associations.**
- **About a dozen hospitals have electronic health records that can be tapped (Judy Ball) for surveys, and there is some evidence that response for such hospitals is better, since no hospital staff time or resources are required to provide such records. There were several controls in place related to security. But as more facilities have electronic records, this will become more standard.**
- **State privacy laws can be problematic for data collection, e.g., Pennsylvania. Sometimes hospitals think there is a problem, but further examination shows that there is none.**
- **CDC's current approach is to get them while they are young by focusing on targeting medical students and training them to understand what health research is. They are looking for other ways to be more attractive to doctors.**
- **Find an individual in the institution who wants to use the data that are being collected.**
- **Hospitals asked for comparison data. Judy can give aggregate data to respondents so that they can compare themselves to others. Judy's response rate is about 50% overall.**
- **Sometimes getting corporate level buy in works, but not always. Generally, letters from the chains are very helpful.**
- **Offering incentives such as press releases for the hospitals, etc., saying that the hospital is participating helps, although NCHS may want to discourage such disclosure because of risks to confidentiality.**

ACTION ITEMS: (Declarative Statements)

- **Start an ongoing workgroup to address participation issues of health care providers.**
- **Solicit state association endorsements when doing surveys, not just national association endorsements. Compile a notebook with other endorsements.**

- **Explore training hospitals about use of data (particularly comparative data).**

Attendees:

1. Sally Gousen
2. Judy Ball
3. Sara Thran
4. Chet Bowie
5. Robert Pokras
6. Robin Remsburg
7. David Kyllo
8. D.E.B. Potter
9. Cathy Burt
10. Elayne Heisler

SESSION TITLE: Tracking New Outpatient Procedures

CONVENER: Tim Carey

There are assorted new outpatient procedures after which people are sent home or sent back to the nursing home. Also there are old procedures which have now become outpatient. How do you track these procedures?

HEADLINES: (Discussion and Recommendations)

- **Listed examples of procedures. NCHS has the ability to collect these data. NCHS is required by HHS to use the ICD-9-CM codes without modification until the CMS/NCHS joint committee on the ICD-9-CM has introduced a new or modified code. But NCHS needs (and likely has) outside support to lobby to change procedures.**

- **Where are things occurring?? Radiology suites, surgical suites, vascular intervention radiology;, outpatient catherization, cardiac catherization, UIR, plastic surgery, GI procedures, pain clinics, outpatient chemotherapy.**

- **NCHS needs input into where to go to ask these questions. Now NCHS goes to facilities certified by the Centers for Medicare and Medicaid Services (CMS). Had to be separate from the hospital, but if the hospital owns the facility, if it is under a separate license, then they classified it as free standing.**

- **Could NCHS compare the data obtained to a claims database to see what they are missing? But if NCHS is using the same codes as CMS until a new code comes out, NCHS is using the old code and would be missing things—ICD-9 CM; still need to record the name of the procedures in order to get at new procedures and their frequency.**

- **NCHS to have an advisory group on new procedures and on new locations where services may be occurring. (Is the current group that makes ICD-9 CM codes sufficient?) (coordinating committee between NCHS and CMS)**

- **Is the problem the codes' not being there, or is the problem that the outpatient facilities are not included sufficiently. Do we need an ambulatory care study?**

- **Are missing changes in numbers of day in the hospital because of replacement by outpatient procedures (length of stay variable becomes challenging because the National Hospital Discharge study is picking up the outpatient clinics, so the 23 hour stays are slipping through the cracks)**

- **How are rehab beds handled? How much is arbitrary? How can these be handled by data collection strategies? Is NCHS' model of a hospital flexible enough? Should the survey be redesigned to reflect the changing nature of hospitals? How do we keep data collection flexible enough? (especially re: comparability to previous waves)**

- **Surveys are by definition behind? Surveys will not pick up rare procedures—so really cannot pick up diffusion or effectiveness…. (CMS needs to deal with a delay are paying for procedures for a few years without any real knowledge about its effectiveness.)**

- **Should NCHS oversample based on ICD-9 codes or based on drug codes?**

  - **Where does something like chemo fall since it is a drug not a procedure? There is more of a continuum of what things are now. How do data collection procedures account for this? There are definitional issues—need to make these decisions. Otherwise, by collecting everything you will overwhelm your survey**

ACTION ITEMS: (Declarative Statements)

1. NCHS should look at the hospital as a whole, while having the flexibility to oversample certain areas and certain types of procedures.

2. NCHS should consider sampling by procedures, particularly in the context of ambulatory care clinics.

3. NCHS should make sure that the data collected from hospitals and ambulatory care clinics can be crosswalked and combined for analysis.

4. The most appropriate coding system should be used, and NCHS should have the flexibility to use codes that they generate? (although this may be challenging in the context of comparability)

5. Does NCHS need an advisory body to discuss new studies, new procedures and new places to examine (to help NCHS keep up with state of the art changes in healthcare – niche and boutique services)?

Attendees:

1 Tim Carey
2 Charlie Adams
3 Linda McCaig
4 Sally Gousen
5 Paul Eggers
6 Bob Pokras
7 David Matchar
8 Irma Arispe
9 Meg Johantgen
10 Jerry Riley
11 James Lubitz
12 Marni Hall
13 Jane Sisk
14 Claudia Steiner
15 Elayne Heisler

SESSION TITLE: Structuring Data To Support National Reporting

CONVENER: Ernest Moy

HEADLINES: (Discussion and Recommendations)

- **There are significant gaps in reporting on race and ethnicity in large national reports.**

- **What are unique benefits/measures from establishment-based surveys that can be used to measure health care quality?**

- **Is it possible in the National Health Care Survey (NHCS) to identify providers and report quality data on providers?**
  (Group opposed)

- **How can we expand data collected without increasing burden on providers and decreasing response rates?**

- **Is there a process for identifying certain core measures from NHCS for future reports?**

ACTION ITEMS: (Declarative Statements)

1. **Explore new sampling methodologies to obtain more cases from minority populations.**

2. **Develop more accurate methods of collecting data on race and ethnicity.**

3. **Develop some standard measures of quality that are measured using the National Health Care Surveys (in contrast to person-based surveys).**

4. **Consider converting NHCS to electronic data collection or web-based data collection.**

5. **Explore process of having an interagency work group identify specific measures from the National Health Care Survey to add to future data collections.**

6. **Prioritize important items, conditions, diseases, or procedures from specific surveys.**

7. **Consider discussing issues at broader policy audiences to identify policy-relevant data.**

8. **NCHS should consider periodicity of component surveys and items.**

Attendees:

1 Trena Ezzati-Rice
2 Susan Schappert

3   Steve Wilkins
4   Amy Chanlongbutra
5   Bill Marder
6   D.E.B. Potter
7   Amy Bernstein
8   Jane Sisk
9   Irma Arispe
10 Julia Holmes
11 Mike McNeil
12 Judy Kasper
13 Linda Bilheimer
14 Dionne Braddix
15 Jean Kozak

SESSION TITLE: Is It Possible and Desirable To Release Public Use Provider Files?

CONVENER: Cathy Burt

HEADLINES: (Discussion and Recommendations)

- **Should NCHS release a file of physician data from the NAMCS?**

- **Nursing Home Survey does release a facility file with facility characteristics, but researchers must use the Research Data Center (RDC) to link it to the patient level data.**

- **Should all the physician characteristics be released on the visit file, but then include a physician sampling weight in addition to the visit sampling weight?**

- **If released as a separate file, what aggregated visit characteristics might be important to add?**

- **Researchers would be interested in, at minimum, a physician file, at maximum a linked data file with the visit data.**

- **Having two weights on a combined file may be confusing to researchers. Might be easier to release files separately and then for those who want to link them, make them use the RDC.**

  - **Discussion of releasing qualitative info about providers for use by consumers. (off topic)**

- **Discussion of widely available electronic medical record data for analysts linked with provider information in the future. (off topic)**

ACTION ITEMS: (Declarative Statements)

1. **Public use file for providers should be released.**
2. **Make THEM use the RDC to link to visit file.**
3. **Evaluate which visit characteristics should be included on the file (e.g., % of non-white patients, average drug mention rate).**
4. **Survey file users for what other characteristics would be desired.**
5. **Combine 2 years of data for a file release.**

Attendees:

1 Genevieve Strahan
2 Abbie Moss
3 Jane Sisk
4 Sara Thran
5 Bernard Bloom
6 Ann Greer
7 Cathy Burt

SESSION TITLE: Collecting Data on Complementary and Alternative Medicine for NCHS Surveys

CONVENER: Morgan Jackson

HEADLINES: (Discussion and Recommendations)

- **Many assisted living facilities and nursing homes are adding complementary and alternative medicine (CAM) modalities through formal programs (Tai Chi, massage, aromatherapy, etc.), but it is difficult to monitor unofficial use.**

- **Data from surveys may under-report use of CAM to the degree that they do not include assisted living and nursing home facilities.**

- **Data on CAM use has broad policy implication as we look at changes in Medicare funding, insurance, and health care expenditures.**

- **Since substances prescribed by a provider are covered by hospice, should CAM interventions be included?**

- **This is a growth area. Do we want to track the increase in prescribed or independent use of CAM? The recent example of hormone replacement therapy is illustrative.**

  - **Differences in definitions of CAM have to be kept in mind in administering surveys. Population characteristics, geography and settings (assisted living, nursing home) impact the definition.**

ACTION ITEMS: (Declarative Statements)

  - **Add CAM questions to existing and future provider and facilities surveys – increasing numbers of nurses and facilities are using them.**

  - **Explore the use of NHCS methodologies to survey CAM providers.**

  - **Explore collaborations with other Public Health Service agencies to increase the knowledge base on CAM.**

Attendees:

1   Morgan Jackson
2   Lisa Dwyer
3   Robin Remsburg
4   Sylvia McSkimming
5   Carina Deans
6   David Woodwell
7   David Kyllo
8   Bruce Stuart

SESSION TITLE: Presenting Encounter-Level Data for Lay People

CONVENER: Amy Bernstein

HEADLINES: (Discussion and Recommendations)

- **How to present NHAMCS? Do you present rates per population? How do you explain age adjustment?**

- **Percent of people for medication from MEPS presented in National Healthcare Quality Report. Rate of antibiotic use for the common cold.**

- **Problem with press: 14% of people had anti-depressant when actually 14 per 1,000 people. How do you get people to understand statistics and how much detail regarding age adjustment? Health US has footnotes.**

- **Quality Report has rates, has subjective measures. National Healthcare Disparities Report tends to talk about relative differences, does not focus on actual rates themselves, but looks at change over time.**

- **Problem occurs when one takes specific number and reports it wrong. Reporters take it from numbers. What is the best way to present data so as not to misinterpret?**

- **Any utilization rate is misinterpreted by some people. Solution: 25% of people made visit to ER, and then this percent made visit.**

- **Problem with encounter data: analysts and the public do not like an isolated event in terms of person's care.**

- **Must accept certain premise: antibiotics over utilized/underutilized. Need to have agreement that then do not have a context to interpret rate.**

- **Utilization rate by itself is not useful. Need comparison in order to make sense. People who are interested in health services research find the number itself important in terms of explaining utilization.**

- **Difficult to determine how many % readmitted. Problems with days of care per population. Average length of stay understood very well.**

- **Problem occurs when the denominator is U.S. population. What is most problematic is explaining why the numerator and denominator come from different sources.**

- **Need to look at men/women over time; looking at rate of treatment.**

- **Physicians want data on people, not visits. What is the best way to present? Should present percent of visits instead of rate per population.**

- **Usually present drug mentions as a percent of visit; number of asthma drugs/asthma visits or percent of visits with asthma drug prescribed.**

- **Rate of antibiotic use has come down.   In comparisons of settings, e.g. NAMCS vs. NHAMCS emergency department or outpatient department, population is the more meaningful denominator for comparison.**

- **When one examines drug visits as a percent of all visits, one measures only those who are in system.**

- **Work harder with reporter? Selective representation of data; if capture those who are not in system, look at population based surveys NHANES, NHIS as starting point.**

- **Population rate is something reporters and policy people need to be educated on. Staffers and Hill people need to be educated on importance of different rates.**

- **AHRQ percentages are better; problems with rate; proportions are much preferred to rates and much easier to understand.**

- **Utilization and expenditure from MEPS; the overall expenditure rate not reported.**

- **Using percent of visits does not account for the fact that some groups have more visits than others, e.g., persons age 65 and older. Even if 72 percent of drug visits have drug mentions, seniors have more drug mentions than children. This pattern comes from the rate of drug mentions per visit, not from the percentage of visits with a drug mention. Different metrics tell different things. Percent may be easier to understand, but may not always be the most meaningful measure of some things.**

- **Must adjust NCHS language to most closely approximate what the public understands.**

- **Age adjustment is more epidemiologist's framework of analysis; age adjustment can be used as analytical point to show what percentage of age group is explaining certain phenomenon.**

- **People do not understand age adjustment. Nor do many analysts do it. Health US uses many footnotes to explain the procedure, although it is unclear who actually reads them.**

- **Rate of population is summarization of visit rate and drug proportion during visit; mentally tell them that depressant use are increasing because visit number is increasing and prescription rate per visit is increasing.**

- **Problem with pitching data to different audiences, academic audience versus public, maybe pitch in middle.**

ACTION ITEMS: (Declarative Statements)

1. **Simplify terms, so that people do not become confused.**

2. **Educate policymakers and press on importance of the data and the meaning of different measures or rates.**

3. **Should not suppress data, because others cannot be interpreted; need to make it more understandable to the public and educate users.**

4. **Find different ways to say a measure to the public (in technical notes, explain utilization rate and why that measure is important); also have concrete examples why a measure is important.**

5. **Explain measures better; dissect measures to explain them in more detail and to explain their relevance and importance.**

Attendees:

1. Charlie Adams
2. Marni Hall
3. Susan Schappert
4. Mike McNeil
5. Cathy Burt
6. Ernest Moy
7. Amy Chanlongbutra
8. Amy Bernstein

SESSION TITLE: Improving Insurance Information To Monitor the Impact of Health Policy Changes on Medicaid and Uninsured

CONVENERS: Judy Kasper and Jim Lubitz

HEADLINES: (Discussion and Recommendations)

- **Accuracy of data gathered on insurance is questionable.**

- **Is Expected Source of Payment the "true" insurance coverage of the patient? Is the problem getting better or getting worse?**

- **Can we improve insurance reporting through linkages with other data sets?**

- **What is the information we would like to obtain on insurance? Information should include patient's insurance information (e.g., xeroxed card) in addition to physician's expected source of payment.**

- **What is the quality of insurance and encounter level data in Community Health Centers?**

ACTION ITEMS: (Declarative Statements)

1. Investigate possibility of doing study on validity/accuracy of expected source of payment
- **Go back after a year and determine whether expected source of payment was accurate, or**
- **Conduct a validation survey comparing MEPS or National Health Expenditures from Centers for Medicare and Medicaid Surveys (CMS) with all health care surveys to compare percentages of persons/visits with particular types of insurance, percentages paid out of pocket.**

2. Investigate possibility of getting information on expected source of payment and patient's true insurance coverage.

3. Investigate possibility of obtaining data on what patient paid for visit (dollar amounts).

4. Consider adding a pharmacy provider survey to NHCS.

5. Consider linking NHCS with administrative data (such as CMS, OASIS and so on) to obtain accurate, more comprehensive insurance information.

Attendees:

1. Judy Kasper
2. Jim Lubitz
3. Julia Holmes

4. Beth Han
5. Jane Sisk
6. William Marder
7. Sara Thran
8. Fred Decker
9. Irma Arispe
10. Jean Kozak
11. Linda Bilheimer

SESSION TITLE: Home and Community Based Care To Measure Quality of Life

CONVENER: D.E.B. Potter

HEADLINES: (Discussion and Recommendations)

- **Population of concern – nursing home eligible or population who needs assistance with activity of daily living (ADL) in a community based setting.**
- **What are the additional data we need?**
- **What do we need to do to reduce or limit emergency room use and hospitalization?**
- **Question – People have multiple needs, how do we best meet them?**
- **Need to measure system capacity at community level.**
- **What are the measures of quality that could change the system?**
- **How do we learn from other countries?**
- **Need to review CMS Outcome and Assessment Information Set (OASIS) data to determine quality issues.**
- **Measure kinds of services at community level.**
- **Measure of continuity of care, transition care, and respite care.**
- **What are the access issues by geography and demographics?**
- **Collect primary and secondary diagnosis – by disease and condition.**
- **Collect Medicare beneficiary claims, OASIS claims, patient interviews, follow-back survey.**
- **Quality of Care – from whose perspectives?**
- **Outcomes – patient – symptom management, prevention of complications.**
- **Main concerns are coordination of care and transition care.**
- **Many workforce issues associated with care for this population.**
- **If we cannot obtain comprehensive data, how can we obtain sentinel event data?**
- **Can obtain event data?**
- **Can we agree on elements, e.g., falls, fractures, pain, decline in ADLs, nutrition, medication, ER, durable medical equipment, track family care as well?**
- **Link with family caregiving association, Alzheimer's association.**
- **Move out of LTC and move to other types of settings.**
- **Challenge – to collect data about process of care.**
- **May be eligible for institutional care, but receive in a variety of services.**
- **What are the care services received?**
- **Home care wellness.**
- **Immunized, exercise, maintain functional status.**
- **What proportion of people have care management?**
- **Home care – Medicare home health benefits.**
- **Area agency on aging.**
- **Reality – of home services.**
- **Medicare only medical services.**
- **Cash in counseling – case manager assesses and you receive allowance to pay for services needed. Intermediary agency monitors.**
- **NHE, and then**

ACTION ITEMS: (Declarative Statements)

- **Develop measures of coordination and transition of care.**
- **Develop measures of continuity of care.**
- **Develop measures to determine access of care (payment and geography).**
- **Develop measures for those on the end of life.**
- **Focus on sentinel events, falls, death of spouse, ER visits, hospitalizations, pressure / statis ulcers.**
- **NCHS provider based surveys.**
- **Link to richest community based data sensitive to demographics, geography.**
- **Take area resource services data and link to include older American Services Act.**
- **Link data with CMS, Home Health, Hospice.**
- **Develop strategies for determining informal or private pay services for non-Medicare and non-Medicaid reimbursed services.**

Attendees:

1 D.E.B. Potter
2 Carina Deans
3 Sylvia McSkimming
4 Dale Lupu
5 Ann Greer
6 Bernard Bloom
7 Tim Carey
8 John Drabek
9 David Kyllo
10 Sabrina Zadrozny
11 Morgan Jackson

SESSION TITLE: Gathering Prescription Drug Data by Brand Name, Generic, Off-Label, etc., and by Customer

CONVENER: Tim Westmoreland

HEADLINES: (Discussion and Recommendations)

- **Rx consumes larger and larger proportion of the health care bill.**
- **Medicare Part D is going to be a natural before-and-after test situation for change in Rx usages (by brand-name/generic usage).**
- **Large changes are constantly being made in FDA/patent policy that affect generic availability and are worth billions.**
- **Payment policy and pricing are issues of constant Congressional and Executive interest.**
- **There are proprietary data bases on these topics (as well as those of drug makers and pharmacies), but they are of limited availability and are expensive.**
- **Note that there are questions of not just what patients are prescribed, but what they are taking: splitting pills, taking others' Rx (and costs)—although NB: providers may not know how patient takes it (or even if they fill), but NHANES may know what person is taking and maybe dosage. Nursing homes do collect what patients take, and maybe brand-name vs. generic.**
- **Ambulatory care collects what is prescribed and taken and over the counter, not what is dispensed; ED prescribed there or given at discharge.**
- **NOTE: NCHS now gets what docs prescribe by brand name, not necessarily whether generic dispensed (and perhaps vice versa)**
- **Could be used as a snapshot of whether people are getting quality care.**
- **There are limitations in the way that docs report what they are prescribing: sometimes they may write brand name, sometimes generic. But computer-assisted prescribing may help with standardization.**
- **AHRQ gathers some data on pharmacies; pharmacies may be an opportunity to get information on label vs. generic; industry captures this already and is quite expensive.**
- **Do we know mail-order and internet (legit) pharmacy information? Or shifts in the market? It may be in claims data.**
- **So many drugs by so many names and therefore many ways to get confused.**
- **We use FDA classification now.**
- **CMS gathers through macro information in National Health Accounts data now— mega data—as well as the Medicare Current Beneficiary Survey (MCBS).**
- **Claims databases capture the brand-name vs. generic usages.**
- **Epidemiological issues and personal issues (interactions, sharing, etc.)**
- **Do you need to photograph the pill bottle? Expensive, not usable in phone surveys, requires face-to-face—but people need these data; but with patient consent, you could get insurance claims data.**
- **There are new e-methods for providers to find drugs and information as clinical support tools. Could these tools be used in research? Does not include off-label uses.**
- **PBM managers do not generally know diagnoses.**
- **Is there information on lab tests—should there be surveys of why tests are prescribed?**

ACTION ITEMS: (Declarative Statements)

- **More public info is needed.**

- **Information on what is already collected by NCHS and others on Rx in the existing surveys should be pooled, and there should be NCHS discussion of what is missing.**

- **A crosswalk of these data should be considered to decide whether data already gathered are comparable.**

- **NCHS should consider using classification systems that Medicare D is developing.**

- **NCHS should discuss with CMS National Health Accounts and CBS how they are gathering their data.**

- **NCHS should contact pharmacists and schools of pharmacy to see what data are needed and what are being used.**

- **NCHS should contact PBMS to see what data are needed and what are being used.**

- **Consider asking docs why they ordered each specific Rx (and thereby gather on-label/off-label) or lab test (and consider whether NCHS is the right venue).**

- **Consider samples, experimental studies, and supplements to test some of these data questions.**

Attendees:

1. Tim Westmoreland
2. Bill Marder
3. Lisa Dwyer
4. Steve Wilkins
5. David Woodwell
6. Trena Ezzati-Rice
7. Tom McLemore
8. Elayne Heisler
9. Paul Eggers
10. Robin Remsburg
11. Morgan N. Jackson
12. Linda McCaib
13. Robert Pokras
14. Meg Johantgen
15. Michael Fitzmaurice
16. Jane Sisk

SESSION TITLE: Accessibility of Data for Policy Makers and Staffers

CONVENER: Dionne Braddix

HEADLINES: (Discussion and Recommendations)

- **What was the original mandate for the surveys?**

- **How have the surveys adjusted to accommodate changes in "points of episode" over time?**

- **It is not about making data available, but about synthesizing them to make them relevant to policy makers.**

- **CDC advocates its priorities, not the priorities of its subsets: to the subsets' disadvantage.**

- **The National Health Care Survey (NCHS) should divert people to analysis of data on main health issues. These people should be ready to research and provide "sound bite" information.**

ACTION ITEMS: (Declarative Statements)

1. **Observe HCUP data sets for example of easily manipulated materials.**
2. **Have web-based canned responses and reports that address basic health issues. These statistics should be easily accessible to policy makers, and should provide basic information on national issues.**
3. **Create the capacity to provide "information" and not just data. NCHS should be the "broker" of information. If they cannot provide the information themselves, they can point you to who is doing the kind of work that is needed. NCHS should look into being the "middle man" between congressional staff and other entities that have data that are useful to them.**
4. **If broker activity is going to occur, make sure it is funded or reimbursed, so that private information providers are willing to participate.**
5. **Reduce barriers that prevent NCHS from advocating for their services. Make sure that staffers know about the services that NCHS provides through yearly visits, packets, for healthcare staffers. (i.e., How can the NCHS help you get the details you need to create policy?)**
6. **Look forward systematically at legislation that is coming up for reauthorization (i.e., Older Americans Act, Title VII, Appropriations, etc.)**

Attendees:

1   David Matchar
2   Claudia Steiner
3   Dionne Braddix
4   Rob Weinzimer

SESSION TITLE: Ongoing Communication

CONVENER: Rob Weinzimer

HEADLINES: (Discussion and Recommendations)

- **Need to emphasize communication more. Shifting resources to technical assistance and analysis may be a better investment, to disseminate information more effectively and show its relevance for policy.**

- **Need to develop constituency and stakeholders.**

- **Develop proactively products that show how NCHS data and products are useful to a corporate CEO, managed care industry, etc.**

- **Offer service to help states and localities generate health statistics, such as NCHS statistics, or do it for them at a cost.**

ACTION ITEMS: (Declarative Statements)

Attendees:

1   Rob Weinzimer
2   Julia Holmes
3   Ernest Moy
4   Susan Schappert
5   Robert Brook

SESSION TITLE: How Can We Make It Easier To Calculate the Cost of Care?

CONVENER: Paul Hebert

HEADLINES: (Discussion and Recommendations)

- **There are many different kinds of dollars that can be calculated: payments versus costs, out-of-pocket cost to recipient, unreimbursed charges. All types of cost information are necessary.**

- **MEPS does this, but it is too small to get at all medical conditions of interest. It would be nice to do it with NCHS databases also.**

- **Home health, hospice, and nursing home facilities collect charges, and will link to Medicare, but not to Medicaid. This is done because they have identifiers. Why not do this for hospital or ambulatory data?**

- **Very little information on costs for hospice care. This limits the types of analyses that can be conducted.**

  - **MEPS had to go to payer or provider to get reimbursement information, which is expensive to recreate in NAMCS, NHDS.**

- **Focus on real costs, not just dollars. How many resources were really used? Why is Minneapolis/St. Paul so different from Miami? Make the data more useful for doing regional analysis.**

- **Linking to local information would be useful. Information on local characteristics, such as geographic labor costs or other area resource file (ARF) variables, would be useful.**

ACTION ITEMS: (Declarative Statements)

- **Link data to local information, and then have the Dept. of HHS set up data centers throughout the country so that researchers outside the beltway can use linked data.**

- **Provide researchers with files that they can link themselves (i.e., average price for a drug, charges and reimbursement for CPT codes, etc.) to create cost variables.**

- **Assign to each ambulatory encounter in NAMCS and NHDS a best estimate—or several estimates--of the cost of that encounter. The researcher can use that cost if he/she wants, or come up with his/her own definition based on linkable databases.**

- **Have a grantee do the above and make it available to all researchers.**

Attendees:

1. Paul Hebert

2. Jane Sisk
3. Bill Marder
4. Bernard Bloom
5. Ann Greer
6. D.E.B. Potter
7. Bruce Stuart
8. Sabrina Zadrozny

SESSION TITLE: Lab Data?

CONVENER: Paul Eggers

HEADLINES: (Discussion and Recommendations)

- **Until there are electronic medical records which you can query in retrospect, it will be hard to get these data.**
- **A big issue here is the fact that lab results come in later than the actual event itself.**
- **Could this be done in the ambulatory setting by giving the provider a self addressed envelope to send on to the survey group when the lab gets in?**
- **Collection of adding more clinical data is being explored for the hospital discharge survey. This research could offer the potential to collect lab data in the NHDS. It is very challenging, but probably would be very useful.**
- **The long term care survey has considered this. What would be the time frame and how would you define it?**
- **Would it be possible to link these data collections to lab data sources.**
- **How widely is LOINC being used? Could this be used?**

ACTION ITEMS: (Declarative Statements)
Check out the "Patriot Act" mortality file as a source of follow-up data linkages – (not relevant to this session).

1. **NCHS should explore the viability of getting lab result data for the HDS, NAMCS, NHAMCS, and long term care surveys.**
2. **We would also like an indication on the NAMCS of "why" a lab test was ordered, not just the ICD9 code.**
3. **NCHS should have more resources to accomplish this.**

Attendees:

1. Paul Eggers
2. Elayne Heisler
3. Mike McNeil
4. Robert Pokras
5. Steve Wilkins
6. Michael Fitzmaurice
7. Jerry Riley

SESSION TITLE: What is NCHS' Primary Mission? Why Should Its Budget Not Be Zero?

CONVENER: Robert Brook

HEADLINES: (Discussion and Recommendations)

- **Issue of longitudinal vs. cross-sectional data. Health-care provider data are now cross-sectional. Longitudinal data could provide an intense look at the community level.**
- **Confusion about surveys. There is not enough push about how to use data from the NCHS health-care provider surveys.**

- **The quicker that data are available, the better.**

ACTION ITEMS: (Declarative Statements)

**1. NCHS should be in constant contact with those who favor a zero budget.
It should be able to make the case to others of the unique, continued value of NCHS in an environment in which people are looking for programs to cut, redundancies, etc. NCHS has unique value in technical expertise, methodology, standards, and analysis of information.**

2. NCHS should offer to help. No problem is too small in health statistics.

**3. Construct matrix of data needs, which agency to do what, and NCHS' role.
NCHS to have part in all.**

4. Offer workshops on use of data from provider surveys at meetings of professional societies, for example, Society of General Internal Medicine, ambulatory pediatrics. Offer more opportunities for training in use of data.

5. Reach out to new Congressional representatives and local health departments.

6. Examine opportunities to build on data collection programs in other agencies, e.g., Veterans Affairs and Department of Defense, and collaborate more with those entities.

7. Expose NCHS employees to objectives, undertake internal marketing on the importance of seeing NCHS role as better meeting information needs.

Attendees:

1. Robert Brook
2. Tom Westmoreland
3. Bill Marder
4. Jane Sisk
5. Paul Hebert
6. Cathy Burt

7. Michael Fitzmaurice
8. Rob Weinzimer

"Closing the Circle" Session

- **83 participants, 30 sessions, 31 hours of discussion; 12 of 30 sessions convened by women.**
- **Information will be used by the Division for making plans for the next 5 years.**
- **Points made during the talking-stick process:**

  - **Making the most of information systems will be a challenge. How can we continue to supplement the information we collect so we can remain relevant?**
  - **We hope that experts will continue to provide input to make the surveys better.**
  - **It has been useful to hear different suggestions, opinions.**
  - **We are looking forward to re-evaluating what has been collected. Good questions were raised about how we can use the data in the future.**
  - **Is there any effort to reduce survey items that have not been useful?**
  - **Electronic health record is only scratching the surface. There is much to do in this area.**
  - **There is a lot at NCHS that many researchers may not be aware of.**
  - **Opportunities for linkage of data sets are important. We should pursue them, and not let the perfect be the enemy of the good.**
  - **Need to look at the advent of the electronic health record and what it means for data availability, future data collection.**
  - **NCHS needs to do more to disseminate information about the surveys. We are looking forward to working with you in the future.**
  - **Collaboration and partnering among federal agencies would be useful and important.**
  - **As output is synthesized, look across sessions, because common themes emerged. Need to keep cross-cutting issues in consideration in the redesign (for example, use of complementary and alternative medicine cuts across surveys).**
  - **Congratulate NCHS for recognizing the importance of looking inward and outward and the trust they have placed in the people they have brought together to provide advice.**

Open Space Forum Attendees

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Sharon Arnold
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Division of Health Care Statistics

Judy Ball
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Amy Bernstein
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Chester Bowie
U.S. Census Bureau

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American School of Clinical Psychology

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